### The National Library of Medicine Fostering High Reliability Health Care Systems

### Patricia Flatley Brennan, RN, PhD Director National Library of Medicine







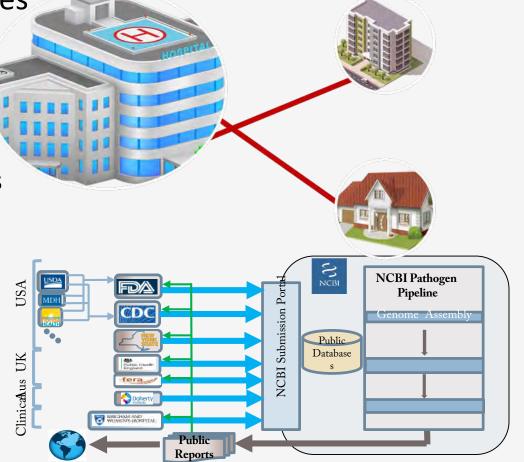
# We're all on a journey together to improve health and health care!





# How does the NLM contribute to High Reliability Health Care?

- Provide Information Resources
- Foster Standards including SNOMED, LOINC and Commercial Data elements
- Conduct research
  - Advanced biological analytics
  - Data Science for every day people
  - Uncover patterns from large data clinical and claims sets
- Serve researchers, clinicians, organizations and society





### ClinicalTrials.gov

A service of the U.S. National Institutes of Health



MeSH on

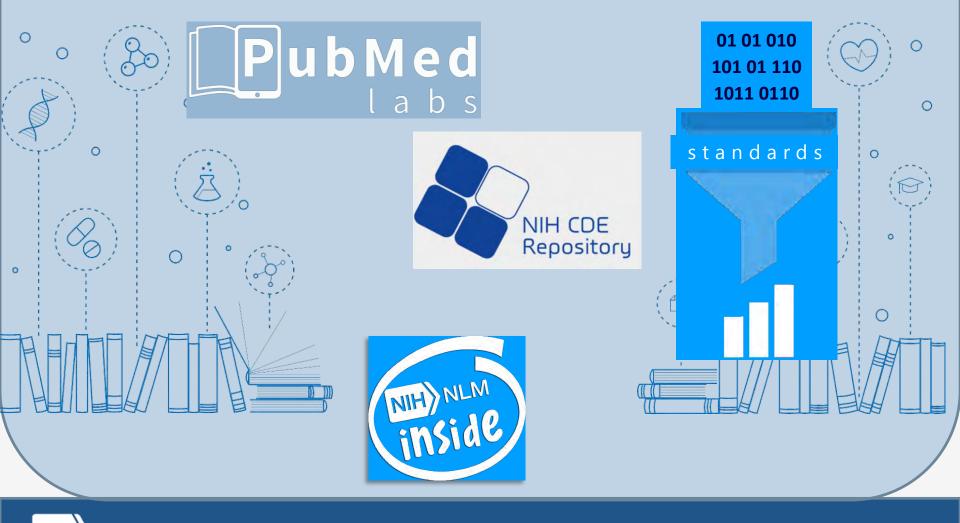
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Search

# What does the NLM do to enhance High Reliability Health Care?

- Enhance Information Delivery
- Promote access to research data
- Foster Common Data Elements
- Curate Value Sets

# **Enhance information delivery**



U.S. National Library of Medicine

# PubMed

#### Literature is the primary repository of knowledge

Publed.gov US National Library of Medicine National Institutes of Health	PubMed	Search
	Advanced	Не



#### PubMed

PubMed comprises more than 27 million citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites.

#### Using PubMed

PubMed Quick Start Guide
Full Text Articles
PubMed FAQs
PubMed Tutorials
New and Noteworthy

PubMed Tools
PubMed Mobile
Single Citation Matcher
Batch Citation Matcher
Clinical Queries
Topic-Specific Queries

More Resources <u>MeSH Database</u> <u>Journals in NCBI Databases</u> <u>Clinical Trials</u> <u>E-Utilities (API)</u> <u>LinkOut</u>



# **NIH Public Access Policy**

The NIH Public Access Policy implements Division F Section 217 of PL 111-8 (Omnibus Appropriations Act, 2009). The law states:

The Director of the National Institutes of Health ("NIH") shall require in the current fiscal year and thereafter that all investigators funded by the NIH submit or have submitted for them to the National Library of Medicine's PubMed Central an *electronic version of their final, peer-reviewed manuscripts* upon acceptance for publication, to be made publicly available no later than 12 months after the official date of publication: Provided, that the NIH shall implement the public access policy in a manner consistent with copyright law.



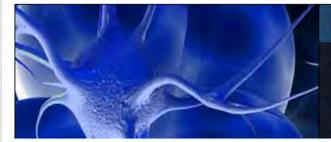
US National Library of Medicine National Institutes of Health

Journal	List	Advanced

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#### Search

Help



PMC

#### PMC

PubMed Central® (PMC) is a free full-text archive of biomedical and life sciences journal literature at the U.S. National Institutes of Health's National Library of Medicine (NIH/NLM).



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#### Other Resources

PMC International

Text Mining Collections

**Developer Resources** 

PMC Citation Search

PMC Accessibility

#### 5 MILLION Articles are archived in PMC.

Content provided in part by:

Journals

2169

Full Participation N

Journals

334 4753 NIH Portfolio Selective Depo

Selective Deposit Journals

#### Public Access Funders and PMC How Papers Get Into PMC NIH Manuscript Submission System My Bibliography

PMCID/PMID/NIHMSID Converter



Search

PubMed Labs Try otitis media treatment koonin e crispr influenza vaccine effectiveness

#### What is PubMed Labs?

PubMed Labs is a test site where we are *experimenting* with new features and tools that eventually may be incorporated in PubMed, in their current or a revised form based on the input we receive. Please try the site and <u>let us know</u> what you think.



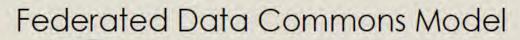


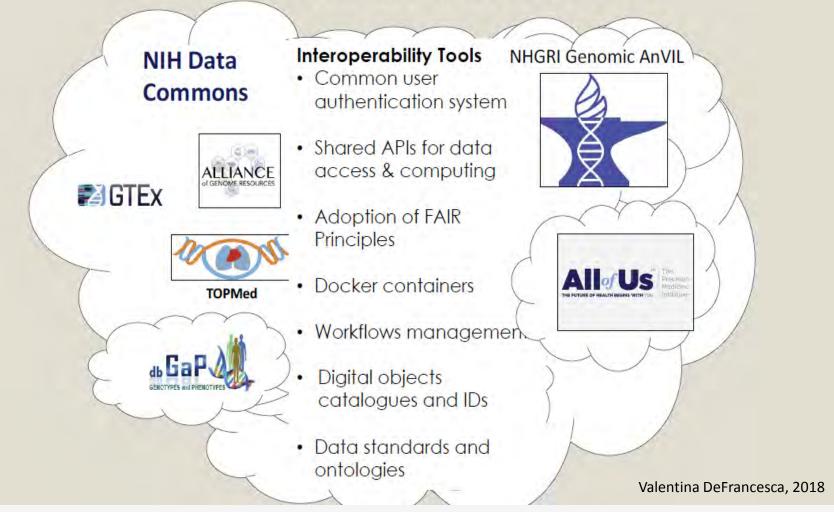
# Relevance based ranking & Snippets

PubMed	influenza vaccine effectiveness		×	Search
TEXT AVAILABILITY	2,361 results	Sort by	Best match	Most recent
Abstract Free full text Full text ARTICLE TYPE	Influenza vaccine effectiveness circulating virus and the effect of Ohmit SE, et al. Clin Infect Dis 2014. BACKGROUND: Each year, the US Influenza of influenza vaccines in Overall adjuste	prior vaccination on es	timates. work examines th	e effectiveness
Review      Clinical trial      PUBLICATION DATE	Effectiveness of seasonal influer people: a meta-analysis of test-ne Darvishian M, et al. Lancet Infect Dis 2014. BACKGROUND: The application of test-neg influenza vaccine confounding bias by r	gative design case-con ative design case-control stu	dies to assess the	e effectiveness of
<ul> <li>1 year</li> <li>5 years</li> <li>10 years</li> </ul>	Efficacy and <b>effectiveness</b> of live children. Coelingh K, et al. Expert Rev Vaccines 2015 Evidence of high efficacy of live attenuated	<i>- Review.</i> I <b>influenza vaccine</b> (LAIV) fro	om randomized co	ontrolled trials is
Reset all filters	Evidence of high efficacy of live attenuated strong for that included 'FluMist', 'LAIV', '			

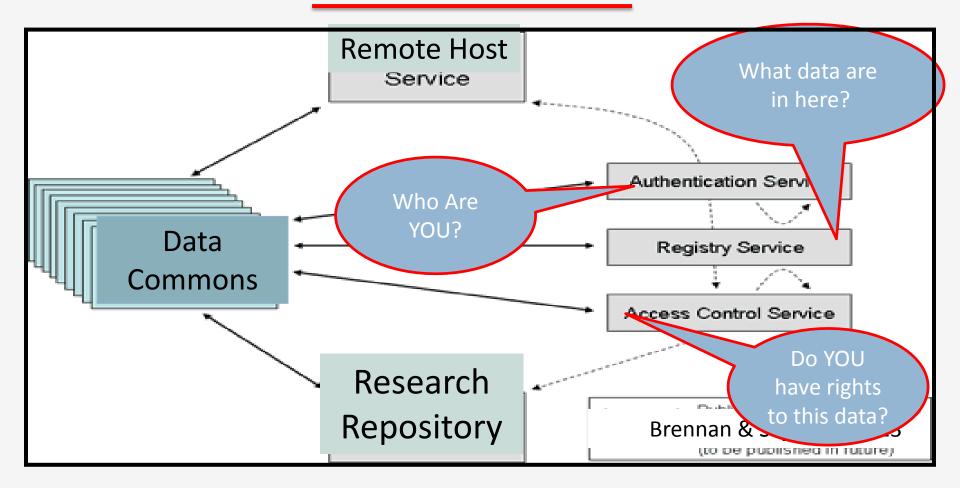
NIH

# **Promote Research Data Access**





# Manage Access and Identity Management at Scale









### NIH Data Sharing Policy

"Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data."

> Final NIH Statement on Sharing Research Data February 26, 2003

> > What You Need to Know for Successful Funding

- **NIH Data Sharing Policy** 
  - Data sharing plan in proposals (unscored)
    - Publishing
    - Researcher Efforts
    - Data Enclave
    - Data Archive
    - Mixed Mode
  - NIH funds can be used to support data sharing

# Data Discovery in PMC & PubMed



U.S. National Library of Medicine National Center for Biotechnology Information







NIH U.S. National Library of Medicine

#### ClinicalTrials.gov

Find Studies -Submit Studies -About Studies -Resources **\*** About Site -

ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world.

#### Explore 279,151 research studies in all 50 states and in 204 countries.

ClinicalTrials.gov is a resource provided by the U.S. National Library of Medicine.

IMPORTANT: Listing a study does not mean it has been evaluated by the U.S. Federal Government. Read our disclaimer for details.

Before participating in a study, talk to your health care provider and learn about the risks and potential benefits.

Status 0			
O Recruitin	g and not yet recruiting studies		
All studie	S		
Condition or di	sease (For example: breast cancer)		
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Other terms 0	(For example: NCT number, drug name, inves	stigator name)	
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### Common Data Elements



Search Common Data Elements

The NIH Common Data Elements (CDE) Repository has been designed to provide access to structured human and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers and other organizations for use in research and for other purposes. Visit the NIH CDE Resource Portal for contextual information about the repository.

The Repository is a platform for identifying related data elements in use across diverse areas, for harmonizing data elements, and for linking CDEs to other existing standards and terminologies, including the value sets in the Value Set Authority Center (VSAC).

#### Search

Search for individual data elements, by definition, users or sources. Search for sets of data elements ("boards") identified by a particular group for a particular use (e.g particular research solicitation).

#### Compare / Harmonize

Analyze and resolve differences between data elements. Assure that your forms are using variables that will be usable by certified EHRs.

#### Create

Draw upon the experience of colleagues and others to design unique data elements and measures.

Q Search

# **Common Data Elements** Make data findable, interoperable

- Structured human & machine readable definitions of NIH CDEs allowing
  - Search for individual CDE or sets per programs
  - Compare & harmonize similar but distinct CDEs
  - Select or create CDEs with minimal duplication

	U.S. National Lit				
Databases	Find, Read, Learn	Explore NLM	Research at NLM NLM for You	Contact NLM	
VIH) co	mmon Data Element	(CDE) Resourc	Home   Resource Summaries   Glossary		

#### Home

NIH encourages the use of common data elements (CDEs) in clinical research, patient registries, and other human subject research in order to improve data quality and opportunities for comparison and combination of data from multiple studies and with electronic health records. This portal provides access to NIH-supported CDE initiatives and other tools and resources that can assist investigators developing protocols for data collection. <u>What is a CDE2</u>

#### NIH CDE Initiatives

#### NIH CDE Tools and Resources

Collections of CDEs that have been identified for use in particular NIII supported. Databases and repositories of data elements and case report forms that may assist research projects or registries after a formal evaluation and selection processes. Investigators in identifying and selecting data elements for use in their projects.



Some NIII programs have issued specific guidance for using CDEs in funded research.

The CDE Resource Portal also includes Other CDE Resources and Relevant Standards. Descriptions of all four groups can be found in the Glossary.

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The CDE Working Group of the Trans-NEH BioMedical Informatics Coordinating Committee (BMIC) developed this Portal to improve the coordination of CDEs. BMIC encourages researchers to use CDEs from the Resources in this Portal where applicable, and to consider existing CDE initiatives before starting additional initiatives.

Are we missing a CDE Resource? Contact us.

Cowright: Brivary: Accessibility: Site Mao, Yiemers and Players U.S. National Library of Medicine, 8600 Rockville Filke, Bethesda, ND 20894 National Institutes of Health, Health & Human Services Treedom of Information Act, Contract Us Last reviewed: 03 January 2013 Last updated: 03 January 2013 First published: 18 June 2012 Metadata/ Permanence level: Permanent: Dynamic Content

# Value Set Authority

Create profiles of clinical concepts to help measure quality and cost of care







# What is a Value Set?

### A *list of codes* and their terms, derived from standard vocabularies, that *define clinical concepts for a particular purpose* (like diabetes, blood glucose tests, antibiotic prescriptions) to support effective and interoperable health information exchange.



# VSAC – Search Value Sets

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	Optic	c Disc Exam for	Structural Abnormalities	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1403	
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# What are Value Sets Used For?

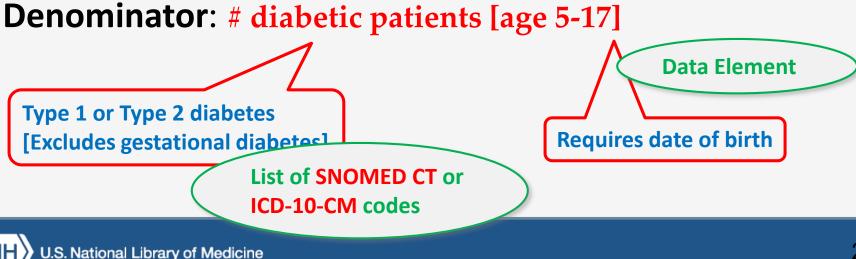
- Clinical Quality Measurement (67%)
- Clinical Data Registries
- Computable Clinical Phenotyping from EHRs
- Public Health Reporting
- Electronic Lab Reporting
- EHR Structured Documents (C-CDA)
- Reportable Conditions Alerts (RCKMS)
- National and International EHR Patient Summary Exchange



# CLINICAL QUALITY MEASURE (implementation)

### Hemoglobin A1c Test for Pediatric Patients

**Numerator**: # diabetic patients [age 5-17] *tested for HbA1c* 



List of LOINC codes

**Tests for HbA1c** 



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A Platform for Biomedical Discovery and Data-Powered Health

#### Strategic Plan 2017-2027

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### **Transforming Information into Discovery**



Accelerate discovery and advance health through datadriven research Reach more people in more ways through enhanced dissemination and engagement



Build a workforce for data-driven research and health

NLMTownHall@mail.nih.gov

H U.S. National Library of Medicine



Accelerate discovery and advance health through datadriven research

### Goal 1

**1.1** Connect the resources of a digital research enterprise

**1.2** Advance research and development in

biomedical informatics and data science

**1.3** Foster open science policies and practices

1.4 Create a sustainable institutional,

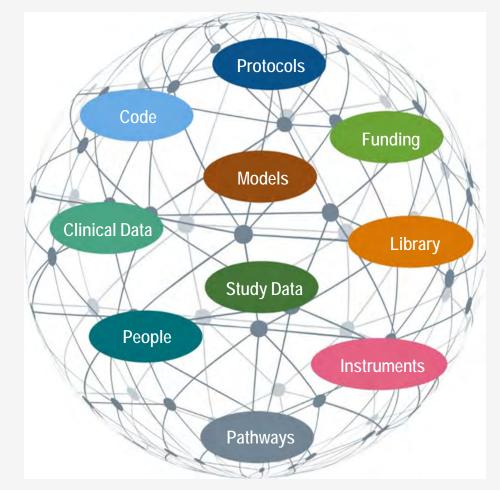
physical, and computational infrastructure





### Fostering a ecosphere of discovery

digital research objects







Reach more people in more ways through enhanced dissemination and engagement

# Goal 2

**2.1** Know NLM users and engage with persistence

**2.2** Foster distinctiveness of NLM as a reliable, trustable source of health information and biomedical data

**2.3** Support research in biomedical and health information access methods and information dissemination strategies

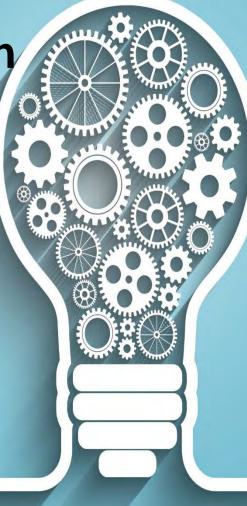
2.4 Enhance information delivery

NLMTownHall@mail.nih.gov

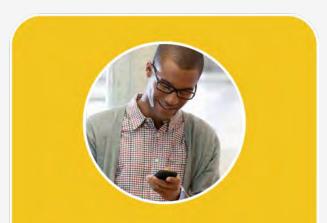
## **The 21<sup>st</sup> Century Collection**

COLLECT | CONNECT | KNOW

- Innovative attribution
- Automated curation
- Personalized presentation & delivery







Build a workforce for data-driven research and health

### Goal 3

**3.1** Expand and enhance research training for biomedical informatics and data science

**3.2** Assure data science and open science proficiency

3.3 Increase workforce diversity

**3.4** Engage the next generation and promote data literacy





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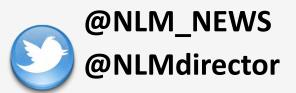




# **Reaching NLM**



Innovations in Health Information from the Director of the U.S. National Library of Medicine





patti.brennan@nih.gov



The NIH is the center of medical and behavioral research for the Nation---making essential medical discoveries that improve health and save lives.

#### Director, National Institute of Nursing Research National Institutes of Health Department of Health and Human Services

Do you have a vision for the future leadership and direction of NIH's National Institute of Nursing Research? Are you a first-rate Scientific Leader seeking a career at one of the preeminent biomedical research institutes in the nation and the world? The Director, National Institute of Nursing Research (NINR) provides leadership, vision, and direction to the Institute and advises the NIH Director and Institute and Center (IC) Directors on the development of NIH-wide scientific initiatives and policy issues related to building the scientific foundation for clinical practice; preventing disease and disability; managing and eliminating symptoms caused by illness; and enhancing end-of-life and palliative care.

We are looking for applicants with a commitment to scientific excellence and the energy, enthusiasm, and innovative thinking necessary to lead within a dynamic and diverse organization. Applicants must possess an RN, a research doctoral degree (Ph.D., or equivalent), in nursing science, omics disciplines, or other relevant biological and/or behavioral science, health services research or social scien disciplines. In addition, applicants must have experience and demonstrated ability in the administration and management of a major national research program. The scientific implications of the integral research programs require extensive experience and knowledge of federal research grants administration. Preference will be given to candidates who display multidisciplinary research interest and/or experience in NINR's key priorities, as outlined in the vacancy announcement.

*The successful candidate for this position will be appointed at a salary commensurate with experience and accomplishments*, and full Federal benefits, including leave, health and life insurance, retirement and savings plan (401K equivalent) will be provided.

If you are ready for an exciting leadership opportunity, please see the detailed vacancy announcement at

http://www.jobs.nih.gov/vacancies/executive.htm

NIH

Applications are due by 11:59 p.m., ET, on Tuesday, November 13, 2018. ational information at SeniorRe@od.nih.gov for questions and/or additional information.

DHHS AND NIH ARE EQUAL OPPORTUNITY EMPLOYERS

- NLM's role in advancing technology, biomedical informatics and tools to supporting nurse
- practice and education. One of the initiatives of this committee is the understanding of technology as an infrastucture to addres Secretary Azar's objectives in healthcare
- National Advisory Committee on Nursing Education and Practice goals:
  - transition of the health care system. The addressed areas identified are value-based care; team
  - based care; IT-including telehealth, data analytics and distance learning; opiods and scope of
  - practice. The scope of nurse practice will address licensing, priveleges, improving national
  - standards based on evidence- culminating in supporting nursing to practice to the full extent of the law at all levels of licensure



# Key points

- Archiving the literature
- Promoting access to the literature
- Data
- Training
- NLM strategic plan

